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End of life care for adult cystic fibrosis patients: Facilitating a good enough death ☆

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Abstract

Background: There is little empirical research on end of life care for CF patients from qualitative, psychosocial perspectives or which examines how staff members manage specific issues raised by cystic fibrosis deaths. This study examined how a number of recent deaths have been handled in an adult CF centre in the UK.
Methods: Multi-perspective psychosocial interview study with patients, staff, and relatives of decedents. Team meetings were observed. Interviews were analysed using a qualitative methodology (Interpretative Phenomenological Analysis). Observational analyses were used to assess the team's interactions when dealing with end of life issues with patients.
Results: Analysis of interviews uncovered themes which addressed the team's questions on care and support of patients with end-stage CF as follows: talking about death and dying; the multidisciplinary team; difficulties for the staff and saying goodbye; active versus palliative care. As a result of psychological input with the multidisciplinary team, staff felt supported and developed the ability to talk openly and in good time to patients regarding their deaths and their wishes for treatment at the end of life.
Conclusion: The team felt that they had reached a foundation upon which to propose a model of care at the end of life for adult cystic fibrosis patients.

Keywords: Palliative care; Psychosocial; Honest communications; Early discussions

1. Introduction

Quality of life and longevity in CF are improving as a result of treatment advances and specialist-centre care [1], however frequent pulmonary infections causing progressive lung damage and respiratory failure lead to patients and the medical team having to consider treatment options, such as transplantation, and to deal with difficult psychosocial issues of death and dying. Consideration of these issues involves the patient, the immediate family, and the staff for a number of months if not years in the period before, during, and after death. Patients who die in hospital, where highly invasive technical treatments are available, may struggle to experience a good death [2]. Deaths are often difficult but opportunities for advance planning, discussion, and integrated care might make it easier for the patient, relatives, and staff.

There are key differences between end of life care for CF patients and palliative care regimens with other groups. CF patients live with the possibility that they may die young, whilst retaining hope of a second chance at life through transplantation; knowledge of this option may hinder

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conversations about dying. The majority of severely ill CF patients are young adults. Some have married and had children, although others still rely heavily on their families for care and support and may well return to the family home when symptoms increase and health deteriorates.

There has been very little empirical work carried out in the field of palliative care and psychosocial support of adult CF patients at the end of life, and to date there are no published guidelines on good practice when dealing with these issues with patients, families, or staff. Some work has focused on palliative care for patients with non-cancer diseases, for example Ludington et al. [3] and Murtagh et al. [4]. One study [5] highlights the difficult end stage symptoms of dyspnoa in patients with lung disease noting the importance of early discussions about end of life decisions. A further study [6] observed that lung transplantation options at the end of life in CF are frequently considered but most patients die before receiving one. Two papers discuss similar issues in the paediatric sphere [7,8].

There is a lack of published material on dying with CF and a key reason for the research was that the team had observed in the past that having conversations about deterioration, death, and dying was difficult. There was a natural reticence of staff and patients to talk about painful deterioration and death scenarios. The team wanted to investigate a number of questions and, following discussions within the multidisciplinary team, EC was invited to interview staff, patients, and bereaved relatives, and observe team meetings. Ethics approval from the local hospital research ethics committee was gained for the study. In the context of a CF adult clinic the team wanted to investigate a number of related questions:

1.1. Talking about death and dying

Is there an appropriate time to talk about death from CF? Are there opportune times to talk to patients and relatives about this? Is the team getting this right from the patient or relative perspective?

1.2. The multidisciplinary team

There is a lack of work that examines staff responses to dying CF patients, or which looks at ways of supporting staff through this time. We wished to examine the value of the multidisciplinary team meeting in supporting members of staff who care for dying patients and also to consider the role of psychology/psychiatry specialists in those meetings, and in changing the culture of acceptance of death and dying more generally within the Unit.

1.3. Difficulties for the staff and saying goodbye

Leading on from this, we wished to see if there were specific areas of difficulty for different staff groups and to see how post-bereavement issues were handled.

1.4. Active versus palliative

Finally, stemming from the palliative care philosophy which has guided many of the recent changes in the centre, we wished to investigate issues around active treatment of patients at the end of their lives and the difficulties relating to discontinuing treatments that were no longer helpful, the involvement of patients in these decisions, and the views of the family.

2. Methods

EC has previously carried out research with the CF centre and the team considered that her familiarity with the medical team, and with the condition of CF, enabled her to carry out this research effectively. As she was not a regular part of the team nor directly involved in patient care, she remained impartial so both patients and staff felt they could discuss the issues openly whilst remaining anonymous; researcher/helper boundaries were not blurred.

The respondents in the study were recruited through a regional CF centre in 2003. They were given information letters and recruitment information. Interviews were conducted with nine members of the multidisciplinary team, six bereaved families, and six patients in declining health. The nine members of the team who were interviewed consisted of two junior doctors, one physiotherapist, one dietician, one consultant, one psychological therapist, two nurses, and one senior CF nurse specialist. Interviews with the staff and patients took place at the CF centre. Interviews with the families took place in their home. The deaths discussed by the families had taken place a number of months previously. Ten unselected routine meetings with all members of the multidisciplinary team were observed to record interactions between the staff during discussions about patients. Similarly, ten ward rounds were also observed. Of particular interest for this study were the discussions held by the team during the build up to a patient death and in the following weeks.

Observations of the team discussions and ward rounds were carried out before the interviews with staff, patients, and relatives. These were not audio taped but extensive notes were taken and written up, checked for accuracy by other members of the team, and used to provide EC with detailed information about the team approach to a patient in declining health. They also provided useful medical information. This enabled her to conduct interviews with patients, staff, and relatives from an informed perspective.

All interviews were audio taped, with consent. The interviews with patients lasted on average 1 hour. The interviews with the families often lasted longer. A semi-structured interview schedule was used to guide the interviews but participants were encouraged to expand on issues that were particularly salient to them. Topic schedules for the groups differed slightly but focused on

end of life care and those things that were done well or poorly, support from the psychological team, and the difficulties of dying from CF.

The interviews were transcribed and analysed using Interpretative Phenomenological Analysis (IPA) [9,10]. The interview transcripts were read repeatedly and analysed for recurring themes. Key words, phrases, and explanations were highlighted, coded as emergent themes, and labelled with a word or phrase that epitomised them. The interviews and thematic analysis were consolidated into a number of overarching super-ordinate and subordinate themes. A number of selected data extracts are shown, chosen because they are key quotations that illustrate the sub-themes. EC discussed the thematic groupings with several of the other authors and with other researchers not connected to the CF world. Where there was disagreement this was usually resolved following discussion. We present here the most straightforward themes that address the issues the team were interested in.

3. Results

The results uncover the model adopted by the team caring for the patient with CF. This section shows the questions the team wanted answered, the key research themes that were shown by the data, and quotations illuminating a number of the themes.

3.1. Talking about deterioration, death, and dying with the patients and family

(Themes: Being realistic, Decisions, Decline, Dealing with the family, Early introduction, Future, Honesty, Hopes and fears, Magical thinking, Myths, Openness, Patient cues, Staff/patient interactions, Taboo, Transplantation).

Our observations of team meetings and analysis of the interviews showed that questions about dying were raised relatively early either by the patient or the staff members. These questions sometimes came at the introductory meetings when the patient was transferred to the adult centre from a paediatric centre, but were more likely at regular meetings such as an Annual Review. At other times, a consultant would wait to see if a patient was ready for such a discussion by their response:

Relative: The consultant was always aware that — she would possibly mention odd things, and I think wait to see if he picked up on it.

Patient: Because I want to ask questions anyway. I've always wanted to know what's going to happen in the future and I know you can't predict exactly what is going to happen, but there's pain and things like that. I've always asked questions and everyone has always answered them.

When the patient did not raise the subject himself, the consultant or psychological therapist introduced the topic early on within the adult clinic so that the subject could be more easily broached, from either side, later, when the need arose. During such discussions, it was important to reassure the patient that talking about death would not hasten it.

Member of staff: I think if they've got questions you've got to answer them. You'll lose their trust if you ignore it or don't answer it or change the subject.

Member of staff: And now, I feel I'm completely comfortable with the patients, and if they want to talk to me about dying and . . . or any issues surrounding that, then I'm fine.

At other times, the subject of death was raised when the patient was declining in health because of not adhering to their treatment. A consultant, senior staff member, or dietician may be the right person to do this. They are in a position to warn the patient of the implications of their current approach to their illness. They can show how a patient's current behaviour can lead to a deterioration in their health, and can seek to identify why the patient is choosing not to adhere to treatment while respecting their decisions.

Patient: They were telling me a good year or before — the doctor kept saying to me "look at these blows" and you're looking at them and you're not really seeing what he's showing you. You are just thinking — you make excuses — you don't wanna compromise to the CF, you don't wanna break to it, but by doing that you are killing yourself — literally. . . I think it's very hard to get people to sit up and understand how harsh CF is at a certain point.

The above quotation illustrates that one of the key issues with patients dying of CF is that because the patient has always lived with the illness, and frequently managed to recover from pulmonary infections, they lead themselves to believe that they can always beat it.

When it was obvious that a patient was concerned and started asking questions about their death, the team recognised the need for a truthful answer. The Annual Reviews provide an appropriate opportunity to talk to the patient about their health, long-term survival, adherence to medication, and any decline in health. Sometimes transplantation needed to be discussed and patients were often shocked that they had deteriorated, and needed time to think about further options.

Patient: Basically it was a year ago last Friday — I had an annual review and I had an absolutely cracking annual review day — blew the best I'd ever blown I thought it was all going swimmingly and basically and six weeks later we go and speak to [consultant] about how the year's gone. And I walked in and she just put it down straight. She was like "look (it totally shook me up) in two years time if you carry

on like this, you are going to need a transplant." It wasn't that you need one today but, you know, if you carry on as you are you are going to need a transplant in two years time. And I was seriously thinking in ten years time, maybe 15. I wasn't feeling that ill and it shook me to the foundations.

Patients in the study frequently reported that their questions were answered honestly and that the staff would deal with difficult questions. The family were also involved in discussions about decline, dying, and death where appropriate, bearing in mind that the patients were adults.

Patient: I ask what my results were and different functions and stuff — no they are pretty up-front with me. . . they are pretty straight to be honest . . . generally pretty up-front.

Patient: They have told it to me like it is. Then if I have to come to a decision they have helped me with the decision. I have asked their advice and they have advised me to do this or that and lots of times I would follow their advice because I trust them and I think they have always been straight with me and there is nothing they have hidden. And even more serious things they have broken it to me gently — let me think about it — I've thought about it — had talks with other people — asked questions — very good.

3.2. The multidisciplinary team

(Themes: Active and palliative, Awareness through the team, Boundaries, Dealing with emotions, Debrief, End of life, Follow up, Known patients a long time, Staff/patient interactions, Support, Taboo).

All members of the multidisciplinary team had contact with dying patients. Education and training is given to facilitate their discussions about increasing symptoms. Training includes communication skills, discussion of grief, loss and bereavement processes, quality of life, hope, pain management, and end of life symptoms.

Member of staff: I now know that what I also needed was educational support for every member of the team so we could learn how to deal with sick young people (which we are very good at medically), and how to deal with them dying appropriately, but deal with ourselves dealing with them dying appropriately, and hence be better at dealing with the families.

Giving honest replies to patients' questions has not always been easy to do and staff have found the overall changing culture in the CF Unit to be a help with this. Centre staff hold regular team meetings allowing everyone time and space to discuss medical and psychosocial issues as necessary.

Member of staff: The changes that I see have been primarily in the staff perception of what palliative care is, how patients manage the change from being in reasonable shape to declining and perhaps going on transplant waiting list, and then either getting a transplant or not, but perhaps at the point where there is end stage disease and then the dying and bereavement processes. So the change is primarily in many of the multidisciplinary team's ability to talk about subjects associated with this, whereas before it was taboo or staff waited for the patient or the family to say something and there was a great sort of stepping on eggshells really. Trying to avoid mentioning the words death or dying, deterioration, or anything that could be construed as distressing for the patient.

The nursing staff felt their input to the meeting was valuable as the patients' social and family interactions often had an impact on their physical health.

Member of staff: It is an open forum and sometimes we do see things that they [other team members] miss. And you do, you do sense sometimes, because you've known [the patient] for a long time, you can sense if there are upheavals at home or things like that, that need to be taken into account, and they need to be addressed in that meeting.

Member of staff: I think it's important to find out what the other team members are thinking, you know, what their needs are, you know, how they're coping with it themselves.

Staff members gained support in their decisions at the team meeting and found the debriefing after a death particularly helpful:

Member of staff: It was nice to get a kind of de-briefing on that — on how the death went. We looked at all the issues, the medical issues, the family issues, the palliative issues and that was helpful to sit back and digest that — and talk it through.

Having a multidisciplinary perspective in the team meetings, and a psychological presence, clarified the team's approach and ensured that the patient did not get conflicting messages. Other members of the staff were able to use the psychological therapist for advice about a patient consultation or noted that the patients had benefited from discussions with her:

Member of staff: I've been and had a lot of discussions in private with [psychological therapist] about it, just about how to best approach things, in terms of talking to someone who's not really ready for the information we're going to give them. And it has been quite useful, yeah.

Member of staff: Patients with CF are quite unique, they have such an air of self-preservation and everything is self-contained. It's like with some of them it's like actually we have to chisel away and find a way in, because they have this sort of like encasing around them that stops anybody hurting them any more than the condition is already, and you really have to work very hard sometimes, to get into them . . . to be able to be there to help them. . . and it takes a very long time to get through to some of them sometimes,

you know, they want to push you away, but they have to come to you on their terms. Now a lot of people have actually experienced [psychological therapist's] input, then a lot of myths and the fear of things have gone and people will actually request to see her.

Time spent discussing the psychological perspective of the patient (relatively healthy as well as dying) had increased over the past few years but especially during the last five years since a psychiatrist and a psychological therapist, working with the palliative care team at the hospital, had joined the team. Several staff members voiced concerns that psychosocial input should not be allowed to dominate over time spent discussing the medical care of the patient and that a balance needed to be maintained, but as the consultant pointed out:

Consultant: The key thing from the patients' point of view is getting the team relaxed about talking about death, dealing with death, so that it becomes as routine as putting a chest drain in.

3.3. What are the particular areas of difficulty for the staff?

(Themes: Active/palliative, Atmosphere on the ward, Boundaries, Funerals, Known patients a long time, Patients as friends, Saying goodbye, Taboo, Transplantation, Youth of CF patient).

Few empirical studies examine staff responses to dying CF patients. Our research showed a number of areas where different staff groups in the multidisciplinary team had experienced problems. Physiotherapists have daily contact with the patient and they continue giving treatments ranging from active chest clearance to simple re-positioning to ease sputum clearance right up to the end of life. As this comment shows, for a physiotherapist caring for a patient who is terminal yet also waiting for a transplant this can be very difficult.

Member of staff: Yes. I mean I've learned my lesson a couple of years ago with one particular patient who we had, as a team, thought was dying. I thought she was dying that day. I gave her the talk and said there really is nothing more we can do, set up some medication, and then half an hour later she had a transplant. Totally out of the blue, and so it does make it very difficult because are we pulling back here or are we still . . . but it's guided by what they want to do. If the patient's still saying I've got to keep going, there might be a transplant, then we'll keep doing that for them. It's different for every patient, it depends on each situation. There have been one or two where I've felt no, I don't think this was right, but if that's what the patient wants to do, then that's what we do. And we discuss it with the team anyway so we work it out from there.

When dealing with a number of dying patients at one time the physiotherapists had recognised the need to rotate the care, and the importance of receiving support within and from outside their own discipline. In addition, it can be particularly stressful for staff members who have known a patient most of their adult lives and where a bond may have been formed. This is something that is not found in caring for patients with other terminal diseases in quite the same way.

The staff felt that they had developed good coping systems and support networks through the team but this could break down when senior staff members were unavoidably absent.

Member of staff: Some of the main doctors weren't around so we had a fairly new doctor, a very good registrar but someone who hadn't really had that much dealing with CF before, and that made a difference because then they were a bit more nervous about it. I do think we're much, much better at dealing with it now both for the patient and for the staff, but I do think there is still the odd occasion when some of the core team aren't there, that makes a difference.

Difficulties had been experienced with rotating junior staff who were occasionally overwhelmed by the process of dying and deaths of patients with CF. An inexperienced doctor on rotation had struggled with these issues without acknowledging a need for support.

The research identified a number of issues for nursing staff. In a small unit, the patients may be very friendly with each other, which can make it particularly difficult for nurses dealing with more than one patient at a time in end stage.

Member of staff — nurse: Some things that make it hard though is having two or more patients going into end stage at one time, and having to deal with two different, two totally different characters, two different styles of family.

Patient: There was one about 3 or 4 years ago that I don't think was handled very well. Because a few of us were very good friends with this person and we were like, not pushed away, but obviously we were not going to have details and things like that because it's confidential, but there wasn't anyone to talk to about it and because some of us were really quite close to this person you know it was very hard for us and we felt it wasn't handled very well but I feel it has gradually got better.

Staff also identified difficulties in passing on bad news to other patients on the ward, particularly when someone goes for transplant and dies unexpectedly; then the atmosphere on the ward changes from euphoria to sadness.

Member of staff — nurse: I think the worst thing I had to do was when I was on nights and we had a very popular lassie went for a transplant and all the patients were up for most of the night, every time I went in to check on them they'd asked me if I had any news. And then at 7:30 I got told that they couldn't stop her bleeding and she'd died on the table,

and I had to go round to give everybody their morning IVs and the first question they asked me . . . and I had to tell them, and I felt so bad, that was the worst . . . and that was about three years ago, and that was the worst case I've ever . . . the worst I've ever had to deal with, telling seven patients (we had a full ward) they were up until 1 o'clock because once, you know, the transplant's happening particularly if the patient is actually an in-patient, there's a lot of things that have to happen and you can't . . . you can't keep it quiet, you can't hide it.

CF patients can deteriorate very rapidly and a patient might die whilst a member of staff is away for the weekend. As the nursing staff may spend a lot of time with the patients and have formed close relationships with them this was seen as a problem. Holding a professional relationship with strong boundaries had been encouraged, but the difficulty of this was recognised and supervision was given to anyone who was having trouble maintaining this. Even staff such as cleaners occasionally found it difficult to deal with the young age of the CF patients and these staff members should not be forgotten.

Member of staff — nurse: You know, the cleaners that go into the room and just recently one of the cleaners actually asked to be moved off our unit, not because she didn't like it but because she couldn't handle the youngsters being so ill, and I think that's something that we probably as nurses feel that occasionally, we're the only ones that have these feelings because we're the only ones that look after these patients, we do all the things for them, and therefore we have this exclusive on how we should feel and it's not that way at all.

In the following quotation the patient acknowledged the difficult job that nursing staff have to do, but he noted how successful they so often are.

Patient: And I walked in and she's on this machine called a nippy and that's like last resort, you know, that's a "keeping you alive machine", and you walk in and it's hard to keep it out of your face that you are shocked that she's got to that point. And I think that the staff do a very good job of doing that. They look past everything that you are strapped to or that you have got attached to you and they still see you. And I think that is really what you need.

The staff now maintain stronger boundaries between themselves and the patients and these changes have been noticed by the patients. This may on one hand seem less friendly but on the other it helps to maintain the psychological health of all and allows staff to continue to provide quality care to remaining patients without becoming overly emotional:

Patient: Yes, there have been a few subtle changes. More professional sometimes in their attitude. Whereas before they would have a cup of tea or something or a chat. Because there are new members of staff now, perhaps staff are a little more professional. Not standoffish, that's the wrong word, just a little more protocol.

For all members of the multidisciplinary team there is a need to say goodbye to the patients for whom they have cared probably over a number of years. The team had recognised the difficulty of maintaining the balance between professional behaviour and care of remaining patients whilst also allowing grief and mourning to be expressed. This can now be openly acknowledged at team meetings and psychological support is available.

Member of staff: It affects everyone that has contact with the patient — and I think years ago we'd probably forget that, but now we make sure that if we've had a death, the day before or the night before, that I go round now and say to everyone — and this isn't something that I've been doing for very long — I go and ask if they are all right, go to the SHO — the young doctor — and ask them if they are fine, I'll tell them that they've handled it very well. Ask if they want to talk about anything. Because it is very much their age group, or younger. But just let them know where my office is, where I am, if they do want to talk.

Dealing with the families after the death and finding them an appropriate space where they can mourn their relative had also been difficult as the next quotations illustrate, but facilities have improved over a number of years.

Member of staff: But the most difficult thing I find about the unit, when that happens everybody knows what's happening and however strong the family think they are, when it actually happens they break down and they break down very noisily and there just isn't anywhere, you know, whichever room they're in it affects everybody and that's the most distressing.

Relative: So then I go round to the pay phone — not far from room 8 where Sheila was, and I still couldn't talk to people privately. And I said to [Consultant] when I went back to see her twice, you know, after Sheila's death, I said if only there could be somewhere private for the patient's family, and patients sometimes, when you're in this kind of situation. They said they had got a room at long last for relatives, that was a start.

3.4. Active versus palliative care

(Themes: Active/palliative, Atmosphere on the ward, Changing wards, Dealing with the emotions, Debrief, End of life, Information — who gets it?, Morphine, Pain, Quality of life, Stigma, Support, Staff/patient interactions, Transplantation).

One area of end of life care that is perceived as particularly difficult in CF relates to the integration of active and palliative care. In CF, active treatment may be

continued almost until the death especially if the patient is holding out hope of a transplant, but the extent of any treatment in the centre was always patient-led with involvement of the family where possible and with relatives often having to make final decisions.

Member of staff: It depends on what we're trying to achieve because although we've had some patients that have been dying, we've been trying . . . they've been on the transplant list and we've been trying to keep them going right up until the day they die, in case a transplant comes up. So, it does depend a little bit on the individual situation, but overall it's guided by what they want to do.

Member of staff: It's not like when you have patients who have cancer etc. where it's a one way street in the sense that the diagnosis and the progression of the prognosis, whereas with CF because it is not always like that, you know, you have got to be careful. But it's a skill and its something that you've got to be able to do.

Relative: It's very difficult for everyone when there is this hope of a transplant — sort of juggling that at the same time. There was always the hope of the transplant but realistically there's also the knowledge that it's not going to arrive.

The team tried to involve the patients in decisions about end of life care at all times.

Member of staff: A lot of the deaths recently have been really quite good. Things have been discussed with the patient and the family and everything is all very above board and everyone knows what's happening.

Patient: My hopes are that I am not in hospital too long. Sounds really silly but I don't want to be hanging around for a long time. Don't want too much pain — that's one of the things — I really don't want to have too much pain. And for them to just be honest with me. If they are losing the battle then I'd rather them just stop. Obviously keep the pain relief. I actually asked the consultant this "has anyone actually stopped medication if they know they are not getting any better and just said stop everything now." And she said it might be something I think about nearer the time if it got to that stage.

It is rare now that a patient comes to the unit in the end stages of dying in a state of ignorance and with their wishes unknown to the team. Where this happened in the past the death was perceived as less good.

Member of staff: I can certainly remember someone early on who reached the point of terminal care without ever having had a proper conversation about treatment options and about how they wanted to live the rest of their life and who basically made decisions — just absolutely stunned when they found themselves in the terminal phase without any preparation.

Member of staff: At that time it was felt by everybody, the team, that this was the right way to do things because the patient and the family had been protected from thinking about things that they didn't. . . But in fact it worked out very badly and the patient was very scared about dying, which isn't to say that people wouldn't be scared about dying, but there was a quality of fear which one would have hoped could have been alleviated if things had been dealt with differently.

The relatives felt that their wishes and the patient's wishes had largely been listened to and respected during this difficult end stage.

Relative: Sheila died on the Friday I think . . . so it would have been the Wednesday evening, I think, the doctor said we really should tell Sheila the situation. And I said well actually she's lived 19 years with hope. I don't really want that taken away from her at this point. And that was fine, as far as I know they didn't say anything, which I was very pleased about.

Relative: And he was hanging on and hanging on, as I say, I think it was probably about the Wednesday they didn't think he'd survive the night, and then [CF Fellow] told us on the Friday he's not going to survive the night, do you want us to resuscitate and I said no, and they just let him go.

Preparing the patient and the family for the end stages of life can be particularly difficult because of the need to balance hope and reality. A death from CF can be very sudden with distressing symptoms. In other cases, the patient may outlive expectations.

Member of staff: I think one of the most striking things about CF is that, because they're young, that last bit, they tend to take longer over the terminal phase . . . things don't close down as quickly as they do in older people, so they tend to die quite a slow lingering death.

Relative: You know, I kept thinking well he's been on IVs before and he'll be all right when he has another course and . . . I mean they're a marvellous team there, and he had every confidence in them. I knew when he went on the oxygen, obviously, things were going wrong, but I still never thought that he would sink so quickly.

Relative: So I think at that point they possibly thought that they might lose him. I remember going in one morning and [the nurse], bless her, put her hand on my shoulder and was . . .and I thought oh, OK, so they think . . . and OK, Felicity was having some trouble breathing and whatnot, but she was still cracking a joke and was reasonably OK, and you tend to just think oh, this is just another hurdle.

As the last two quotations illustrate, it can be especially difficult for the family to understand that a patient has finally reached the stage when they can no longer fight off

an infection after they have spent their whole lives successfully fighting infections.

Sometimes also, even with explanations, relatives may find it hard to understand the reasons for certain actions by the team. For example, our research suggests that if patients had to be moved to a different ward at a late stage for non-invasive ventilation where they may be treated by unfamiliar staff, the reasons for these moves were not always clearly understood by the families and such moves could cause upset and upheaval.

Relative: Yes, I would have to say that was probably the worst time. I think it could have been only three days there, it just seemed like an awfully long time. But no, he hated it. Hated it. And couldn't understand why he was there because, in fact, we didn't see anybody, we didn't see . . . nobody . . . you know, the staff from the CF Unit would come down to see him to say hello, but he never saw anybody specific . . .

Interviewer: So that move was never really explained clearly to you?

Relative: No, I don't suppose it was really. That's interesting isn't it? He was put on the nippy, so we were moved up to the respiratory thing, I think, to try and get it all settled down, but he still saw the same physio and we didn't see anybody else, and no, you're right, it wasn't really.

Where a patient chose not to go on the transplant list their decision was respected by the team and all their questions were answered. One patient who had refused a transplant felt that although the staff in the unit were supportive, it was the other patients who did not understand their reasons.

Interviewer: You don't feel that there was ever any pressure on you to sort of say that you would have a transplant?

Patient: Not from the doctors or the nurses really but there is a kind of a — a lot of people don't understand why I am not going for one. I've got quite a few things from the patients you know. They say that it is up to you, it's your decision, but they really, some of them can't understand it.

Following the death of a patient the family may return to discuss the case with the CF Consultant. Questions about a patient's death were always considered carefully but could not always be answered, an issue that the families understandably found hard.

Relative: So half of me has to say well she died peacefully, she didn't have to struggle after she came out of theatre, but then even though we had several journeys to see the surgeon, who was delightful, and we saw [consultant] who again was very kind, nobody can tell us why. And that to me is — its unfinished, you know we asked all the usual questions — were the organs out of the body too long? Was it too long with them coming? What happened? And they just don't know.

The families were also offered a home visit by the senior liaison nurse who can take away any unused medications but whose function is primarily to give bereavement support if this is needed.

4. Discussion

The staff attitudes to end of life care are crucial in supporting dying patients and their families and are facilitated by a strong multidisciplinary team. The results showed that staff and patients in this CF Unit were comfortable with an approach to death and dying that emphasises the early introduction of discussions and an open and honest dialogue. This may be particularly important with CF because patients may suffer symptoms, such as haemoptysis, that are extremely distressing for patients, relatives, and staff, and there are decisions to be made about supporting a patient at the end of life with morphine. It is important that the team is confident in discussing these issues, can approach the situations calmly, confidently, and maintain a professional attitude. Psychological input at team meetings, individual supervision, and advice over specific patients has been integral in changing the culture of death, dying, and bereavement in our centre, and this in turn has enabled the staff to deal with these issues better.

Problems were sometimes seen with junior rotating medical staff and staff who may be similar in age to patients with CF. Junior doctors are likely to manage better if they are open with more-experienced colleagues about difficult issues as they arise; perhaps through a discussion in the team meeting, problems can be aired, discussed, and support given. New doctors should not be left to make decisions about treatment and care at the end of life without support from senior core team members.

Support for the consultants is an important feature in team care for the patient and this had not always been recognised. There is a strong network within the CF world for medical advice but consultants can very rarely ask for support over decisions about psychosocial issues at end of life. In this team, the consultants also had ready access to a psychological therapist or psychiatrist for support for these issues.

There has been a lot of discussion within the CF unit about how best to facilitating appropriate goodbyes and closure for the staff. Attendance at individual patient funerals by members of staff was not encouraged. There is now an emphasis on equality of respect being shown to each patient who has died so that no one patient is seen to be a favourite or otherwise. This ensures that staff remain aware and conscious of the appropriateness of their interventions and interactions. For these reasons private rituals and ways of saying goodbye have been facilitated instead. Senior medical staff also arrange and attend a biannual memorial service, which is open to any staff member, where the families of patients meet with the staff who cared for their relative.

Diagnosing dying [11] is difficult in CF and it may be difficult to convey this to relatives. We observed, for example, that no matter what care had been taken in giving information, it could not always be fully assimilated by the relatives. Discussing death or discussing a future decline need not be seen as a 'negative' view of CF. It is possible within the context of modern CF care and improvements in survival to discuss life and death issues realistically with adults who wish to make treatment decisions. As most deaths occur in adult units, it is appropriate for adults to wish to clarify their prognosis and to have an open discussion with their CF physician about this. The integration and overlap of palliative and active care throughout the life of a CF patient allows both the patient and the team to adapt to progression of the disease. Integrated active and palliative care is continued throughout the patient's life and up to their death but with the emphasis on one or the other varying according to circumstances. The overall feeling from the team is that they are successfully dealing with these issues and that there is less need to bring in other sub-specialists for end of life care although the hospital Palliative Care Team is always available for advice on symptom control and the team's psychological therapist is a member of that Team.

The method of gathering data from three groups of respondents and using observation to ground the research in its early phases was extremely successful. It provided a broad range of views, on a difficult subject, that largely converged to highlight the changes in the Unit, successful or unsuccessful practices, and areas where changes could be made.

5. Recommendations

Senior core team members should come to agreements with patients about treatment and care at the end of life. The Annual Review would be an appropriate place to begin these discussions to provide an opportunity to discuss death, dying, and transplantation early on when the patient is well and to reinforce to patients where they are in the disease continuum.

Treatment decisions at the end of life should never be left with inexperienced staff.

Holding a professional relationship with strong boundaries with the patient is to be encouraged and supported whilst acknowledging that long-term relationships may well have been forged through the years of a patient attending a clinic and the in-patient unit.

Integration of principles of palliative care with active treatment should be attempted wherever possible whilst acknowledging the difficulties of bridging a patient to transplant.

Family members should be involved in discussions about the dying patient wherever possible bearing in mind confidentiality/consent issues with adult patients and their difficulties in understanding that their relative may not fight the latest infections off as they have previously.

Greater consideration should be given to ensuring relatives understand the information provided by the team particularly if this involves moving the patient to a different ward for additional treatments.

The multidisciplinary team need to meet regularly to develop individualised management plans for in- and out-patients who are deteriorating.

It is important that *all* members of the multidisciplinary team receive peer support through regular meetings and also that they receive confidential clinical supervision to enable them to deal appropriately with dying patients with confidence and care.

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Further reading

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